Research Participation

Step 1  
Register Online
Create an account for yourself. Data will be stored securely without identifiable information.

Step 2  
Consent for Research Participation
Consent to share your information, provide an optional blood sample, and be contacted for future research studies.

Step 3  
Add a Child with a Genetic Disorder
If you have a child who has a genetic disorder, add them and complete their consent.

Step 4  
Submit a Lab Report
Upload your or your child’s genetics lab report. Our genetics team will review it to make sure you’re in the right place.

Step 5  
Share Your Medical History
The Annual Medical History Survey will ask questions about pregnancy and birth and all medical and developmental issues for the person with the genetic condition.

Step 6  
Take Online Surveys
Check your Simons Searchlight dashboard for surveys.

Step 7  
Provide a Sample for Research Storage
If interested, your family may participate in a blood draw. Scientists may use these samples to learn more about the genetic disorder.

Step 8  
Continue Participating
We regularly include surveys, some repeated annually, including a follow-up medical history survey, to track changes over time and enhance our learning.